

# Caregivers' Perceptions of Hospital-Based Dental Care for Their Autistic Children

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## INTRODUCTION

Autism is a growing neurodevelopmental disorder with increasing prevalence. According to the 2019 Canadian Health Survey on Children and Youth, 1 in 50 children aged 1 to 17 in Canada were diagnosed with Autism Spectrum Disorder (ASD), while in British Columbia (BC), 1 in 37 children were accessing funding as of 2020. BC Children's Hospital (BCCH) functions as a primary, secondary, and tertiary care center and serves as the main referral facility for children with behavioral challenges requiring dental care. Despite this, caregivers of autistic children continue to face significant challenges in accessing dental providers who can adequately meet their child's needs.

## OBJECTIVES

Dental care for autistic children presents unique challenges for the child, the caregiver, and the healthcare provider.

The objectives of this study are as follows:

- Assess caregivers' perceptions of dental care for autistic patients at BCCH Dentistry
- Evaluate satisfaction with providers, facilities, and programs (e.g., desensitization)
- Identify improvements to enhance care delivery
- Explore ways to improve interactions with dental staff
- Assess plans for transition to a dental home at age 17

## METHODS

A custom survey consisting of multiple-choice questions and free-text boxes was approved by Quality Insurance/Quality Assurance data management group at BCCH. A convenient sample of 1044 caregivers of autistic children who attended to BCCH dental department were invited to fill out the survey by direct emails and a QR code displayed in the dental clinic.

**Inclusion criteria:** Child must have a confirmation of diagnosis of autism and be a patient of BCCH dental department.

**Exclusion criteria:** Caregivers who did not provide consent to participate or who are unable to communicate in English were excluded from the study.

Survey instruments included:

1. Background information
2. Dental History
3. Preparation
4. Satisfaction
5. Post-graduation dental care (if applicable)

De-identified responses were collected using REDCap. Categorical responses were analysed by frequency and text boxes were analysed by theme.

Analysis: Background instrument gathered data on age of diagnosis. Dental history instrument verified type of visit, referral source and reasons for no past dental care. For preparation and satisfaction instruments, caregivers answered questions about their in-person or virtual health visits and satisfaction towards environment and services. For children 16 years and over, caregivers answered questions about aging out of system.

## RESULTS

A total of 486 caregivers responded to the survey (~43% response rate) and 21 answered the dental transition questions about aging-out-of-system. The average age of autism diagnosis was 3.79±2.42 years agreeing with the Canadian national average. We found that ~16% of caregivers said they had no past dental care for their children. The main barrier was the behavior of their child (70%) and the secondary reason was that dentists in their community were unwilling to see their autistic children. Despite the underutilization of the systematic desensitization program, caregivers reported significant benefits from participating and expressed a desire for more opportunities to access the program. The majority of caregivers (76%) of autistic individuals 16 years and over felt they are ill-prepared to transition their child out of BCCH, mainly because they cannot find a suitable dental home. Overall, there was high satisfaction (88.3%) with the BCCH dental services.

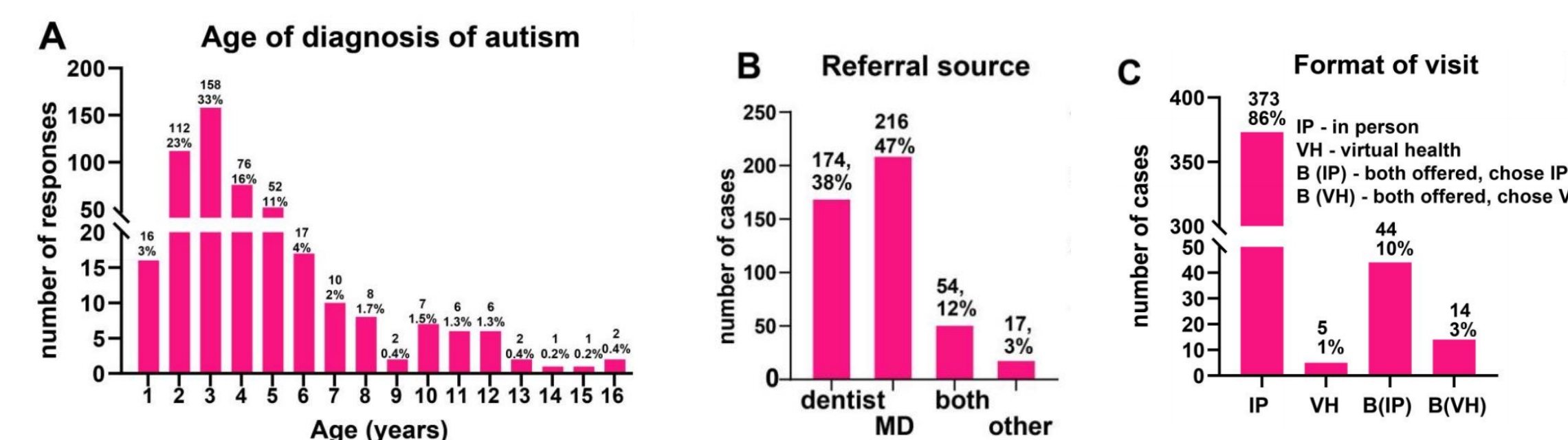


Fig.1 - Background and Dental History. A) Age of diagnosis (years), B) Referral source, C) Type of visit

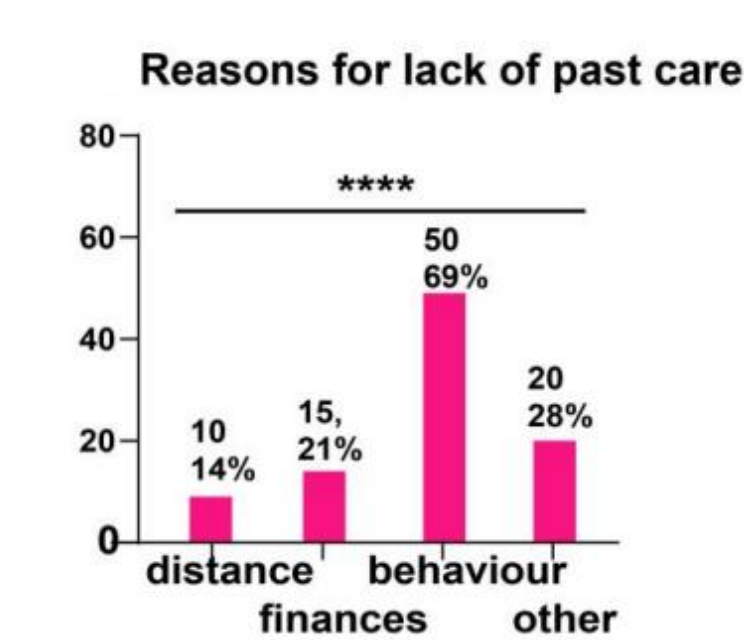


Fig. 2 - Dental History. Barriers to past dental care

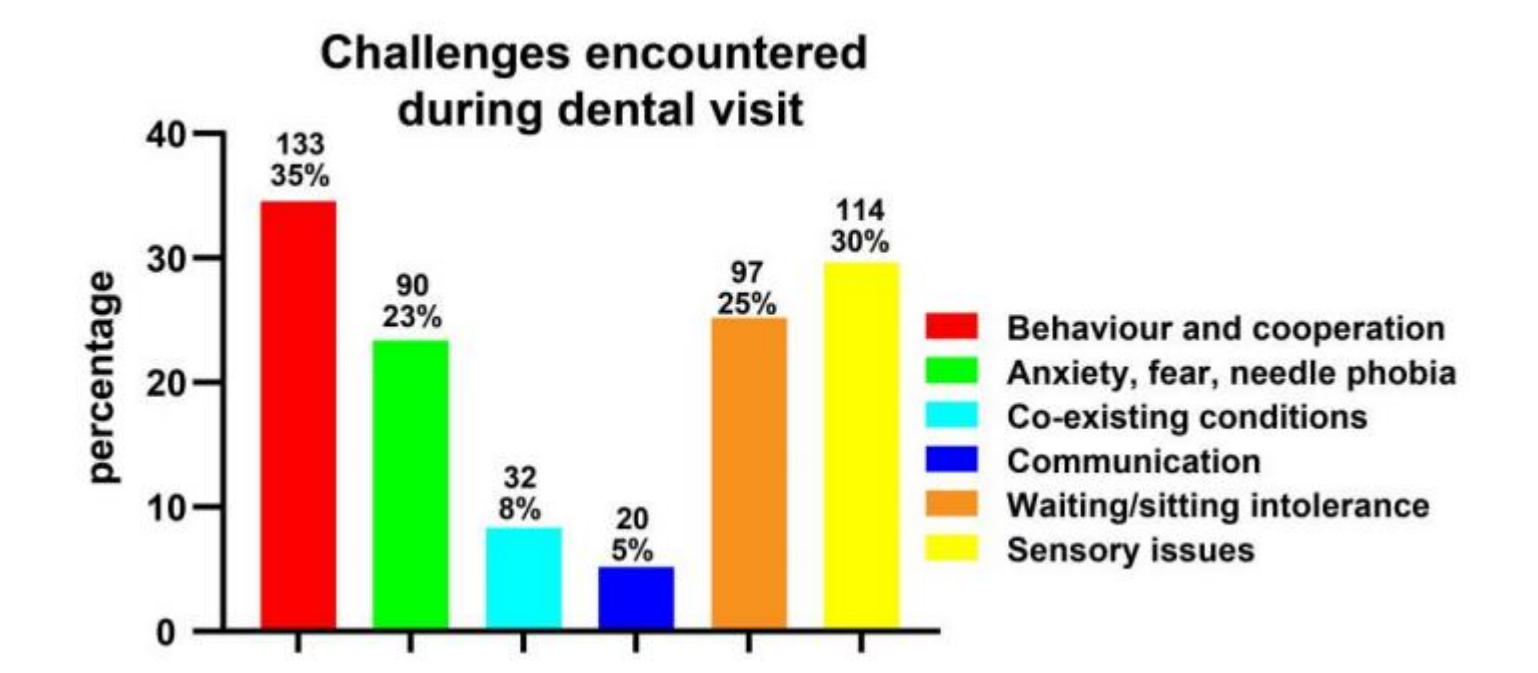


Fig. 3 - Preparation - Challenges during dental visit

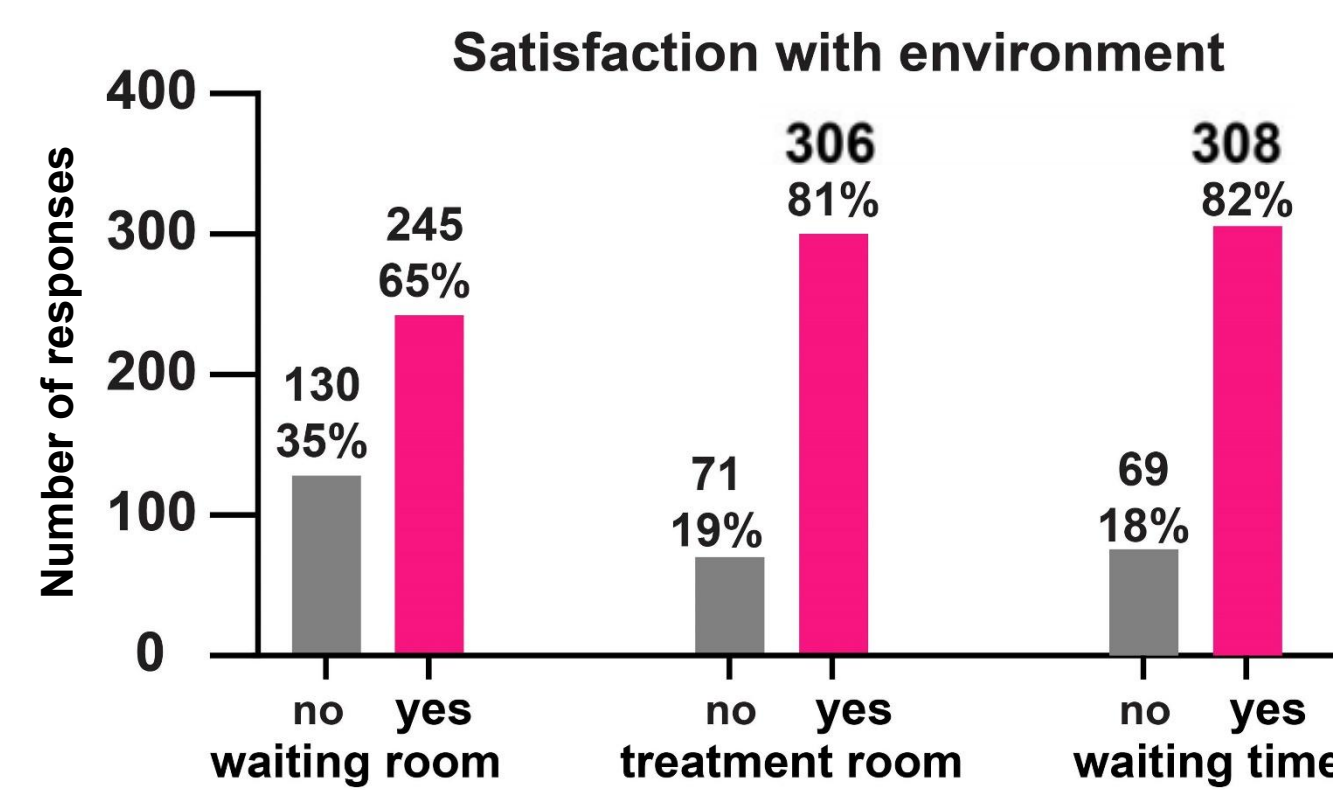


Fig. 4 - Satisfaction with environment

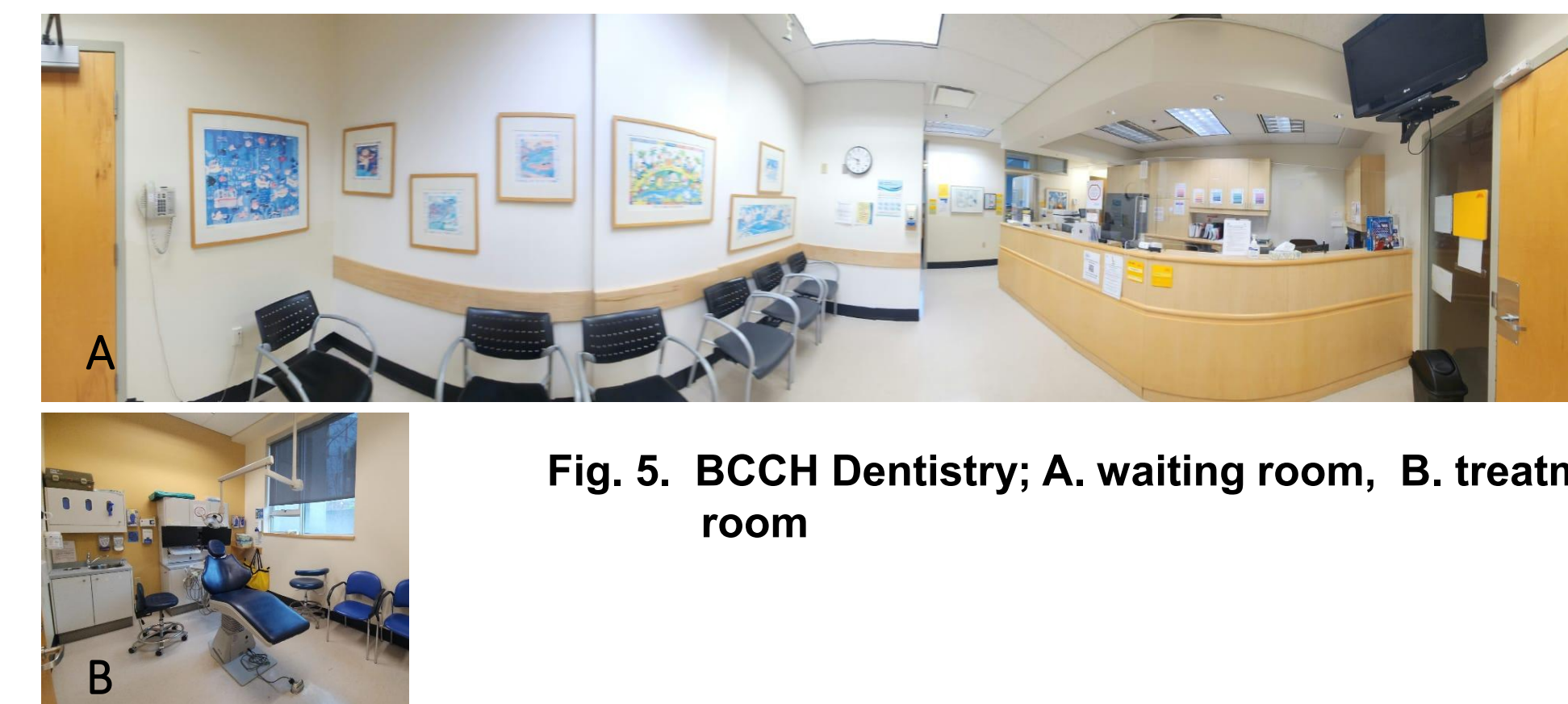


Fig. 5. BCCH Dentistry; A. waiting room, B. treatment room

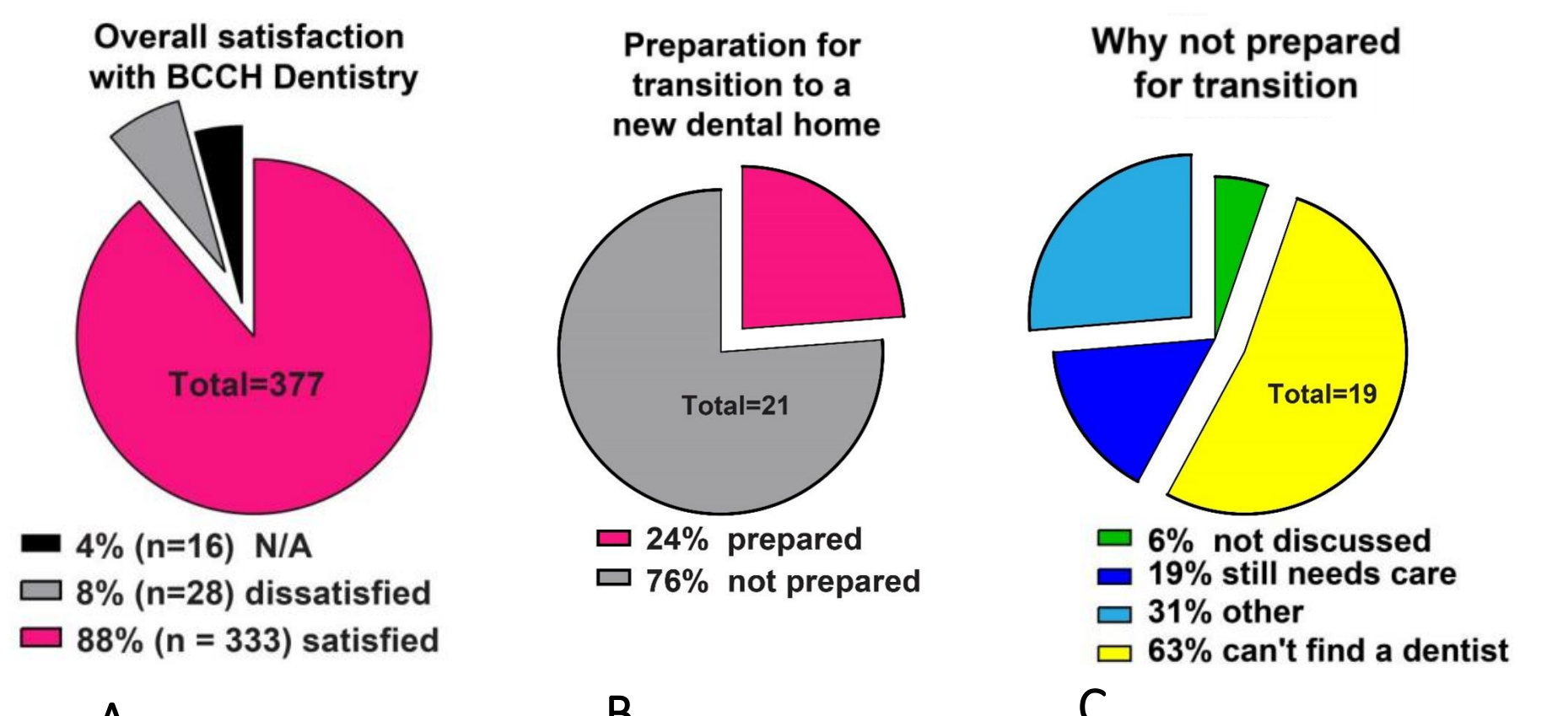


Fig. 6 - A. Overall satisfaction, B. and C. Transition to new dental home

The 777 free-text boxes identified areas for improvement such as keeping the visits short, adapting the environment to sensory needs and improving staff training.

"Because the dental clinic was at children's hospital, I expected the Dentist and staff to be experts in dealing with special needs and specifically autistic children and how to support the children through procedures but I haven't found that to really be the case. It takes a lot of hard work to support these kids, especially with these highly sensitive and protective nervous systems. It takes a lot of creativity, patience and regulating of the adults nervous systems. Parents are a key piece and they need to feel supported. Preparing parents for what to expect, in detail, at dental visits so that their uncertainty is reduced and then they can support their children with more confidence. Think about NUTS, New/Novel, Uncertainty/Unpredictable, Threat to the ego/lack of competency, Sense of loss of control. How can we mitigate each of these. For some just the drive to the hospital and walking in the building is triggering. This is the challenge and disability of autism and that needs to be fully understood and accepted. Thank you for asking the questions."

"I am grateful we are able to access the dental clinic at Children's. My kids would not have appropriate dental care otherwise. Everyone is always kind and helpful but it is very difficult to manage them."

"We didn't have access to dentist yet since we are new to Canada"

"Since my child has Autism, it is hard for him to co-operate in regular dental office, like cannot keep month open for a bit longer, cry, moving around ..."

"The waiting room is the definition of an environment that is not conducive to children with sensory issues."

"We still have one appointment left with you and then we'll go, but we wish we could stay with you forever as this has been a dream for my child to have you."

## CONCLUSIONS

Results will be used to design a new BCCH dental clinic space utilizing Sensory Adapted Dental Environment (SADE), enhance services with pre-visit questionnaires, streamline systematic desensitization, and implement staff training in autism. Our study highlights a major barrier to care. Caregivers are unable to find a dental home in their local community for their autistic children. Our transitioning process has been reviewed to include dental practitioners throughout BC that are comfortable seeing autistic individuals. Better training for dental students and practitioners would also improve access to care. Please watch Adam's First Dental Visit video



## ACKNOWLEDGEMENTS

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## REFERENCES

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